



CONFRONTING STRUCTURAL RACISM NIH Holds First Town Hall on Achieving Equity

BY CARLA GARNETT

Recognition of a disorder is the first step to fixing it.

From witnessing blatant discrimination of Black patients as a medical student to being unfairly segregated within a county's public school system to being rejected as a resident physician by a White ER patient, top NIH leaders told personal stories of racism they had experienced firsthand. The message was clear: Structural racism had affected nearly all, even if its harm was obvious to only some.

Instead of shrinking from the problem,

NIH now seeks to take the first step and confront it head on.

At an Apr. 30 virtual Town Hall on Achieving Racial Equity, NIH director Dr. Francis Collins introduced the issue of "achieving racial equity at NIH and at the institutions we fund" as one "of paramount importance." He described the recent social climate in the United States that pushed the need to address racism urgently.

"Nearly a year ago," Collins recounted, "the murder of George Floyd became one more example of a seemingly endless procession of senseless deaths of Black, African-American, Hispanic and Latino men and women in America.



NIH director Dr. Francis Collins convened a virtual town hall to discuss structural racism and how to end it in biomedical research.

The impact was felt around the world. Recently we've also witnessed a disturbing rise in violence against Asians. Furthermore, the ongoing plight of Native Americans in our country cries out for justice."

In addition, he continued, nationwide, actions and events reflecting bias seemed to have metastasized to target immigrants, people with disabilities, sexual and gender minorities and people in other marginalized groups.

"Structural racism—let's name it—persists, despite decades of civil rights and other movements to eliminate oppression," Collins said.

SEE TOWN HALL, PAGE 4

THE ROAD TO RESILIENCE

Ungar Uncovers How Kids Find Strength in Stressed Environments

BY DANA TALESNIK



Dr. Michael Ungar

In many ways, the Covid pandemic has tested the resilience of people of all ages, everywhere. Its many stressors have taken a toll on our mental health and placed a disproportionate burden on the most vulnerable populations.

Whether in a pandemic or other challenging circumstance, research shows there are strategies to help even the most vulnerable survive and thrive in the face of adversity.

SEE **UNGAR**, PAGE 6

'A MAGICAL PLACE'

Children's Inn Advances Clinical Research by Supporting Patients, Families

BY ERIC BOCK

For three decades, the Children's Inn at NIH has helped to advance medical research by improving the lives of patients enrolled in clinical research studies and their families, said NICHD director Dr. Diana Bianchi.

"The inn improves the quality of the entire experience not only for the patient him- or herself but also for extended family," said



Kristal Nemeroff has been enrolled in an NIH clinical study since she was 7 months old.

SEE **INN**, PAGE 8



Not the Hokey Pokey. Construction Safety Week aims to keep workers healthy on the job site. See more on p. 12.

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ORWH Hosts 2nd Lecture in 'Diverse Voices: Covid-19' Series, June 24

On Thursday, June 24 from 1 to 2 p.m. ET, NIH's Office of Research on Women's Health will host "Analysis and Action: Applications of Intersectionality in Covid-19," the second lecture in the Diverse Voices: Covid-19, Intersectionality and the Health of Women speaker series.

This virtual presentation will feature two speakers. Dr. Lisa Bowleg of George Washington University will discuss her commentary, "We're Not All in This Together: On Covid-19, Intersectionality and Structural Inequality," published in the *American Journal of Public Health (AJPH)*.

Dr. Tonia Poteat of the University of North Carolina at Chapel Hill will speak about her *AJPH* article, "Navigating the Storm: How to Apply Intersectionality to Public Health in Times of Crisis."

ORWH's Diverse Voices series aims to disseminate key Covid-19 research findings that are relevant to diverse groups of women and incorporate a multidimensional



Dr. Tonia Poteat (l) and Dr. Lisa Bowleg will be featured in an upcoming presentation hosted by ORWH.

sex-and-gender focus. Speakers present, in plain language, specific takeaways from their publication for researchers, clinicians and the public.

To participate in this webinar, register at https://nih.zoomgov.com/meeting/register/vJIsce2urDwjGUOB7CXzPx-ET5ft_pBDbrCM. More information about the event is available at <https://orwh.od.nih.gov/about/newsroom/events/analysis-and-action-applications-intersectionality-covid-19>.

Have You Spent Your Time Teleworking Growing Houseplants?

Being indoors over the past year has drawn many of us to houseplants and indoor gardening. If you've started or added to your collection during the past year at home and would like to share photos of your favorite plants with us, we'd love to feature them in the *Record*.

If you would like to participate, send a high-resolution color photo with a brief caption explaining what the plant means to you to nihrecord@nih.gov. Bonus points if you give us the plant's scientific name!

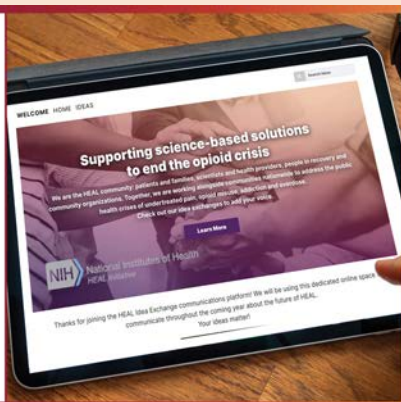


A reader heeded the *Record's* call for plants and sent a photo of this African violet also known as *Saintpaulia ionantha*. "My mother loved them and always had several of different colors in the house. This is one of mine," noted Melissa Yorks, a longtime NIH'er now retired and working for NLM as an indexer. "We put in all those index terms you see in PubMed."

Deadline: June 1

HEAL Wants Your Ideas

The NIH HEAL Initiative is conducting an Idea Exchange, "Moving HEAL Research Into Action," to gather public input that will help shape future directions for the initiative.



HEAL is focused on advancing pain management and finding solutions to address the opioid crisis. All are invited to participate, including the many individuals and organizations on the front lines of the opioid crisis—treatment providers, advocates and families, law enforcement professionals, first responders,

policymakers and government health officials. Practitioners, join the conversation. Share your expertise about how research can inform solutions to improve pain management and the prevention and treatment of opioid misuse and addiction. Submission deadline is June 1.

LOOKING BACK, SPRINTING FORWARD

One Year of RADx Tech Success

BY PATRICIA WILEY

Thinking back to a year ago when terror struck worldwide and the full weight of the Covid-19 pandemic began to set in, NIH quickly mobilized on multiple fronts—one of which was the Rapid Acceleration of Diagnostics (RADx) initiative, with the goal of helping to meet the huge demand for fast, accurate Covid-19 tests.

Fast-forward 1 year and about 300 million Covid-19 tests, NIH director Dr. Francis Collins and NIBIB director and RADx tech lead Dr. Bruce Tromberg hosted a RADx Tech Town Hall to commemorate the anniversary milestone. Last month, about 460 members of the RADx team were able to join the virtual event to celebrate the landmark.

Collins kicked off the event by reflecting on when then-U.S. Sen. Lamar Alexander (R-TN) asked whether NIH could help produce more Covid-19 diagnostic tests, which were desperately needed. Collins immediately thought of Tromberg because this was, after all, an engineering problem.

Tromberg described an existing structure at NIBIB that develops new diagnostics for infectious diseases, and thought it could be the perfect springboard to launch a larger, Covid-focused effort. To their surprise, NIH was allocated \$1.5 billion to solve the diagnostics crisis and produce tests to help change the course of the pandemic.

“I was really excited and a little bit terrified—promising we could do things that I wasn’t sure were even possible,” Collins recalled. “But I need not have worried, because the RADx team we celebrate today had all the moxie necessary to deliver the results we needed.”

Next, listeners heard from Alexander and U.S. Sen. Roy Blunt (R-MO) on the genesis of RADx from their perspective, how it has impacted the pandemic and what is in store for its future.

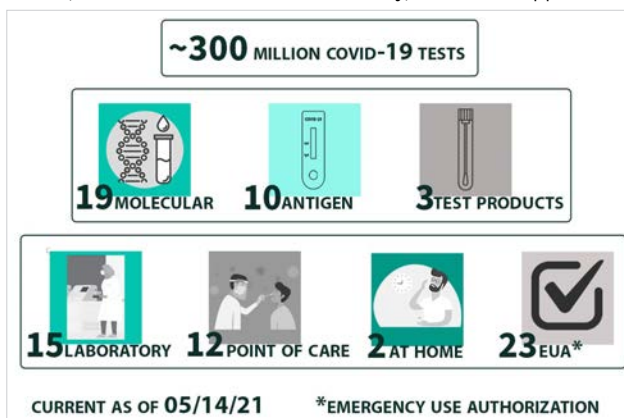
Alexander highlighted the millions of tests RADx is producing each day, including at-home tests that take only 15 minutes. He underscored the continued importance of Covid-19 testing, even in light of the vaccines.

Blunt could not remember the last time someone complained that there weren’t enough tests—because now there are enough tests, thanks to RADx. He said scientists and innovators answered the RADx call for new technologies, and looking forward, he hopes the RADx model can be replicated for other health problems.

Next Tromberg recollected events from last year—specifically Apr. 24—the day Congress earmarked \$500 million for NIBIB for Covid-19 diagnostics, which effectively doubled its normal budget. He

underlined the importance of collaboration and coordination among NIH, the White House, HHS, BARDA, FDA, DoD and CDC to increase the U.S. testing capacity by more than 240 million tests (as of March 2021).

Collins then introduced Carole Johnson, national testing coordinator for the White House Covid-19 Response Team. She applauded the incredible work of the scientific community, which has supported



a significant increase for testing, one of President Biden’s key response pillars. She highlighted the success of the RADx model and how its public-private partnerships have been essential in accelerating the diagnostics pipeline and will continue to benefit the country long after the pandemic has ended.

Next to present was Ingo Chakravarty, the CEO of Mesa Biotech—a successful RADx Tech company. Chakravarty recounted his tenure with the firm, which started only 2 short weeks before Mesa applied to RADx. At that time, he said they were only capable of producing about 16,000 Covid-19 tests per month, considered themselves under-resourced and had just 65 employees.

Fast-forward 10 months and they have produced more than 1 million Covid tests, have hired 1,200 employees and been acquired by Thermo Fisher—thanks to the support from RADx. “There’s a saying about building an airplane during flight,” he concluded. “What we’ve collectively done here is even more difficult. We have built a rocket ship during launch. I want to say thank you. It’s been an honor. Let’s make a big impact on the American people.”

The final presenter of the day was Dr. Harvey Fineberg, president of the Gordon and Betty Moore Foundation and former president of the National Academy of Medicine, who provided perspective on the value of RADx.

“The RADx program represents government at its best,” he said. “When the history of America’s response to the Covid-19 pandemic is written, two outstanding scientific achievements will stand out—the development of a safe and effective vaccine within a year and the acceleration of diagnostics.” He finished by emphasizing that the RADx process can be used beyond Covid-19, for diagnostics for precision medicine and precision public health.

Joining the Q&A discussion were Radm. Michael Iademarco, director of the Center for Surveillance, Epidemiology and Laboratory Services, and Dr. Tara Schwetz, former associate deputy director at NIH now working at the White House Office of Science and Technology Policy. She discussed how the other components of the RADx initiative leverage the infrastructure of its tech.

Iademarco conveyed the importance of increasing U.S. testing capacity in case a second wave hits and remarked that RADx has been a vital and central player in building U.S. capacity.

In a true celebratory spirit of RADx’s success, Collins played *Covid Lemon Tree* on guitar with lyrics written by Dr. Carrie Wolinetz, and Tromberg rewrote lyrics to a classic Bob Dylan song renamed *Covid Testing Blues*, as program credits scrolled on screen, like the ending to a movie. **R**



ON THE COVER: *Retina showing reticular pseudodrusen. A clinical study led by the National Eye Institute will follow 500 people over 5 years to learn more about the natural history of early age-related macular degeneration (AMD). By using the latest technologies to visualize structures within the eye and measure their function, researchers hope to identify biomarkers of disease progression, well before it advances to late-stage disease and causes vision loss.*

IMAGE: NEI

The NIH Record

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NIH National Institutes of Health
Turning Discovery Into Health

Town Hall

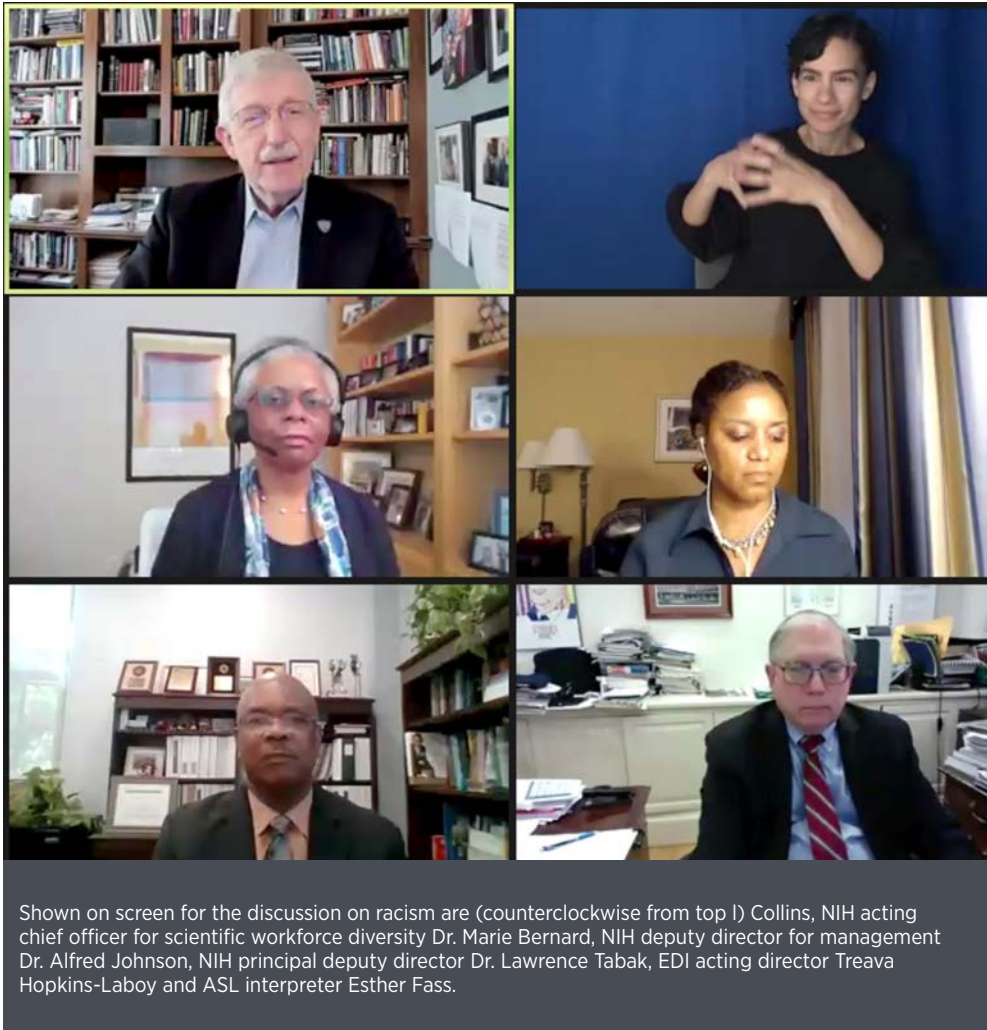
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Structural racism is defined as “policies and practices entrenched in established institutions that result in the exclusion or promotion of particular groups,” he said. “Within our own biomedical research enterprise, structural racism limits access to funding, to training and to employment opportunities for far too many underrepresented groups. NIH alone can’t fix more than 400 years of structural racism, but we can do our part with the resources of the world’s largest supporter of biomedical research.”

The town hall was NIH’s first ever to confront racism so directly. Collins said efforts discussed at the meeting “represent our shared commitment to address structural racism within the biomedical research enterprise. Our ultimate goal is to achieve racial equity. That is the condition in which one’s racial identity no longer predicts how one fares. We’re not there yet.”

After recounting her experience with racism as a youngster, Treava Hopkins-Laboy, acting director of NIH’s Office of Equity, Diversity and Inclusion, presented workforce data that offered evidence of Collins’s point about NIH’s current position in achieving racial equity. Black, African-American, Hispanic, Latino, and Native American employees are vastly underrepresented in the scientific workforce and administrative positions of power and authority.

“This data is sobering,” she pointed out. “It clearly showcases the racial imbalance



Shown on screen for the discussion on racism are (counterclockwise from top l) Collins, NIH acting chief officer for scientific workforce diversity Dr. Marie Bernard, NIH deputy director for management Dr. Alfred Johnson, NIH principal deputy director Dr. Lawrence Tabak, EDI acting director Treava Hopkins-Laboy and ASL interpreter Esther Fass.

Tabak, who talked about candid discussions NIH leadership had with two self-assembled entities—a group of senior, tenured African-American scientists and “8CRE,” a group presenting eight changes for racial equity. He

nature of a hard-wired system that maintains the status quo.”

He also serves as one of three cochairs of UNITE, a five-committee group consisting of a cross-section of NIH’ers from all 27 institutes and centers that was set up several months ago to guide the agency’s long-term initiative to end structural racism.

UNITE is an acronym for the five target areas and major strategies of the initiative: U-understanding stakeholder experiences through listening and

that exists at NIH. We are committed to transparency. With the help of the entire workforce, we’re enthusiastic about moving forward with efforts to enhance diversity at NIH.”

Also speaking to the online assembly was NIH principal deputy director Dr. Lawrence

said NIH owes the groups a debt of gratitude for their honesty and courage in sharing their insights.

Reflecting on his own professional journey and lessons from the past year, Tabak said, “What I have learned is that I don’t really understand the insidious

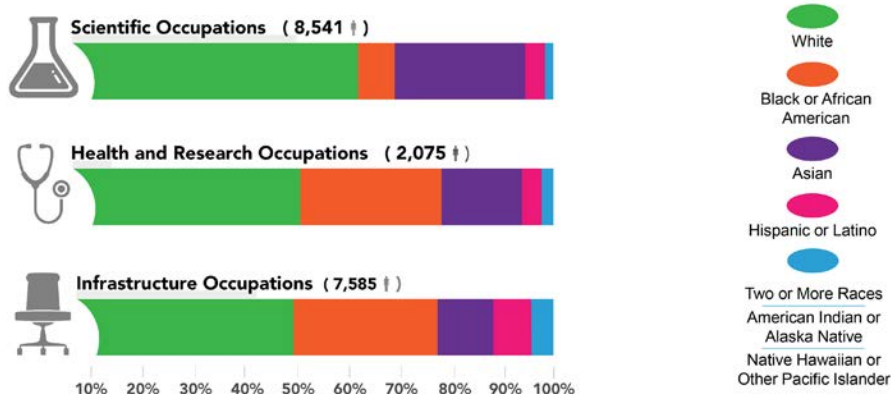
learning; N-new research on health disparities, minority health and health equities; I-improving the NIH culture and structure for equity, inclusion and excellence; T-transparency, communication and accountability with internal and external stakeholders; and E-extramural research

★★★
“Help us to sustain these efforts to dismantle structural racism and achieve our goal of producing equitable power, access, opportunities, treatments and outcomes for all. The consequences of structural, interpersonal and institutional racism are very real.”

-NIH DIRECTOR DR. FRANCIS COLLINS

★★★

NIH Workforce Categories by Race/Ethnicity



Total workforce = 18,201 (excludes 2 employees with missing workforce category). This report only includes information on full-time equivalent employees. Employees classified in the five racial groups or Two or more races are all non-Hispanic or Latino. Employees classified as Hispanic or Latino may identify with any combination of the five racial categories. Commissioned Corps and Advisory Council members are excluded. Data source: HR-44 nVision as of 9/30/2020.

Produced by the Office of Equity, Diversity, and Inclusion: Data Analytics Branch.

2

NIH workforce data show employees represented in several occupational categories.

ecosystem—changing policy, culture and structure to promote workforce diversity.

UNITE's other cochair, NIH deputy director for management Dr. Alfred Johnson and NIA deputy director Marie Bernard, who also serves as NIH acting chief officer for scientific workforce diversity, also talked about experiences with racism from their own lives.

"Although we will not solve all the structural problems that led to these experiences," Bernard said, discussing the basics of UNITE, "I think we can make significant strides to making NIH the ideal institution where all—regardless of race, ethnicity, sex, gender, abilities, past background—are equally valued and able to contribute to our enterprise."

Johnson agreed, describing concrete actions the committee is taking already. "UNITE is determined to acknowledge and detail where we are," he said.

It was the sharing of personal stories that seemed to resonate most with the audience, however. A majority of respondents to a survey after the town hall cited hearing participants' own experiences as having an impact. Presentation of the NIH workforce

data also was noted by respondents as beneficial.

"We are listening to all of you and we are acting," Collins said, concluding the meeting. "Throughout this process we promise to reflect on our actions. When we make missteps—and we will—we will acknowledge

those mistakes and with your help and insight will try to redirect ourselves and act accordingly...Know that this is just the first of many town halls on this topic. Help us to sustain these efforts to dismantle structural racism and achieve our goal of producing equitable power, access, opportunities, treatments and outcomes for all. The consequences of structural, interpersonal and institutional racism are very real."

More than 7,800 viewers tuned in live, with an additional 700 people watching later, on demand.

Weeks before the virtual meeting, organizers had

asked via all-staff email for questions that could be answered during the town hall. Staff submitted 320-plus queries that were grouped into 27 frequently asked themes. Even after categorizing similar questions, only 16 were able to be answered during the



Hopkins-Laboy presented workforce data. Black, African-American, Hispanic, Latino and Native American employees are vastly underrepresented in scientific and administrative positions of power and authority.

VOLUNTEERS

Healthy Volunteers Needed for Bone Marrow Samples

Healthy volunteers are needed for a research study collecting bone marrow samples. Samples will be used for clinical research in the Hematology Branch and are indispensable for many research projects, including studies of normal and abnormal blood cells in the human body, blood diseases, the role of the immune system in marrow failure, and the genetic risk factors for aplastic anemia. Contact the Clinical Center Office of Patient Recruitment at 1-866-444-2214 (TTY 1-800-877-8339) or prpl@cc.nih.gov. Online <https://go.usa.gov/xHgDt>. Refer to study 07-H-0113.

People with Crohn's Disease Sought

NIAID is seeking people with Crohn's disease. Researchers are investigating whether Vorinostat is safe for people with Crohn's. Participants will receive maintenance therapy with Stelara after successful treatment with Vorinostat. Study-related tests, medication and procedures are provided at no cost. Call the Office of Patient Recruitment, 1-866-444-2214 (TTY 1-866-411-1010). Online <https://go.usa.gov/xsRg8>. Refer to NIH study 17-I-0101.

Sickle Cell Study Needs Participants

NHLBI invites people ages 18 and older with sickle cell anemia including HbSS, HbS-β0 thalassemia to participate in a study evaluating the best non-invasive predictor of renal function. Results of this research may help ensure the most accurate assessment of kidney function. Compensation provided. For more information about study 19-H-0100, call 1-866-444-2214 (1-800-877-8339 TTY/ASCII) or visit <https://go.usa.gov/xmFYg>.

Ungar

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Creating the conditions for resilience involves all kinds of positive forces interacting, said Dr. Michael Ungar, director, Resilience Research Centre and Canada research chair in child, family and community resilience at Dalhousie University in Halifax, Canada. Speaking at a recent NIMH Director's Innovation Speaker Series lecture, Ungar discussed efforts to bolster resilience in high-risk environments, especially among children.

Ungar told stories of resilience based on his extensive clinical research and from discussions with colleagues from around the world. While working with a researcher in Japan, for example, he learned that after the 2011 tsunami, an NGO (nongovernmental organization) built an after-school tutoring center, creating a social space and sense of much-needed normalcy and optimism for children recovering from loss.

"They actually created the structure of putting kids back into educational pathways that are predictive of a positive outcome," said Ungar. In another setting or culture, other kids may respond better to different types of programs. The key is finding the right outlets that kids would find most protective to them.

In some societies, promoting resilience requires a mindset change. When university professors in Afghanistan deliberated over how to encourage more women to attend college, they first had to overcome the barriers of a patriarchal society. When women began enrolling at one university,



Children in Botswana have fun working in teams at a camp for kids whose parents died of HIV/AIDS.



Ungar chats virtually with his colleague in Botswana, Dr. Masego Katsi.

an important resource was missing there: women's bathrooms.

"In part, [resilience] is gut and perseverance," said Ungar. "But it's also whether or not somebody builds you a toilet."

In high-risk environments, access to resources—adequate housing, transportation, scholarships, training—can boost resilience, helping people transition to the next phase in their lives. In the face of significant

adversity, said Ungar, resilience is the ability "to navigate to all the psychological, social, cultural and physical resources that sustain our well-being, and our capacity to negotiate, to ask for those resources to be given to us, in culturally meaningful ways."



Ungar says resilience is like a tangram, in which people have all kinds of strengths they piece together in complex patterns that satisfy specific contexts.

Ungar identified 7 resilience-promoting processes, based on patterns he observed in an 11-country study of kids in high-risk environments. The young people who excelled, said Ungar, had access to basic necessities—

shelter, food, clothing, education—and could nurture relationships; negotiate a positive identity for themselves; connect culturally; and experience efficacy, a sense of belonging and a sense of social justice.

"Resilience looks different for different populations in different contexts

for different levels of stress," Ungar said. Whether a refugee fleeing persecution, a person coping with terminal illness, or an average kid struggling with parents' unrealistic expectations, each person pieces together a combination of these resilience factors to cope as best they can.

Unfortunately, research shows many high-risk kids may not be getting the services they need. One Canadian study that was replicated in four other countries revealed that kids from the most dangerous, threatening environments were either not getting services or not benefiting from the services provided. But when children had a positive experience with a therapist or other helpful service, "that was a vehicle for them to find those [resilience-building] factors," he said, to develop that sense of belonging and cohesion. "And then, they would change their behaviors."

In Botswana, Ungar's colleague Dr. Masego Katsi developed a successful resilience-building program to help children

whose parents had died of HIV/AIDS. The children were paired with paraprofessionals in their communities who went on to lead them in team-building and trauma therapy activities at a 2-week camp, then continued to meet with the kids back home.

“By making resources available and accessible to very vulnerable children in a low-resource context,” Ungar said, “she’s making it possible for these children to find the supports they need in culturally relevant ways.”

Building resilience is a dynamic process. Ungar advised asking which program, for which people, at what risk profile will produce the desired outcome.

“I think what we do as clinicians is try and elevate people...try to get them to find socially more desirable ways of expressing or finding connections,” he said. “That could be an online community, a gaming community, maybe a volunteer activity or a faith community.”



Ungar on resilience

The Covid pandemic exposed people of all ages to extreme stress and anxiety. A large U.S. study by CIGNA found that the global health crisis affected older adolescents and young adults the most from a mental health standpoint.

“They weren’t able to socialize,” explained Ungar, “and...some of the social justice issues, such as the Black Lives Matter and #MeToo movements, were worrying them a great deal.”

And yet research also showed many kids were thriving, safe at home, having even the partial attention of teleworking parents without the overscheduling, bullying and other pressures in normal times.

“I think the onus now,” Ungar concluded, “is to allow the science to work with children who are indigenous and from other ethno-racial groups whose experiences are much more marginalized—and explore [these] children’s experiences during the pandemic—and let the complexity of those stories really shine.” **B**

Artist Hill-Edgar To Deliver 5th DeBakey Lecture, June 3

Dr. Allison Hill-Edgar, a 2020 NLM Michael E. DeBakey fellow in the history of medicine, artist and independent scholar, will give the 5th annual Michael E. DeBakey Lecture in the History of Medicine online on Thursday, June 3 from 2 to 3:30 p.m. ET. Her talk, “Dissecting Gender: Reframing Anatomical History Through the Female Body,” will be live-streamed and archived by NIH VideoCasting.



Dr. Allison Hill-Edgar

The female body has been a part of anatomical history from its inception, but usually as the reproductive other to the male body. Hill-Edgar’s presentation re-examines the Western anatomical tradition through the lens of the female body in order to elucidate factors that have framed our understanding of and approach to gender differences in medicine and society.

Drawing primarily on images and sources held by the NLM History of Medicine Division, she will share an array of often marginalized anatomical works, and highlight many of the related subjects, patients, medical practitioners, anatomists, artists and activists. This archival analysis reveals the impact of anatomical visual history on current culture and medical practice today.

Hill-Edgar, a visual artist working in New York City and affiliated with New York Academy of Art, and the Fenimore Art Museum, Cooperstown, N.Y., graduated magna cum laude from Harvard College in 1994, where she majored in fine arts. She also has studied the human body from a scientific perspective, earning her M.D. from Columbia College of Physicians and Surgeons in 2003, completing her medical internship at Columbia Presbyterian Hospital and obtaining her medical license in 2004.

NLM DeBakey Fellowship Now Accepting Applications for 2022

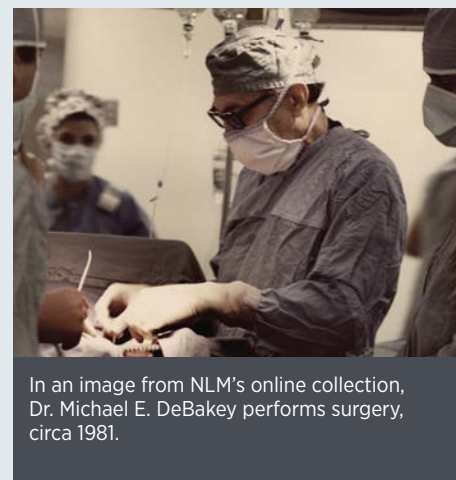
The National Library of Medicine has announced that the application period is open for its Michael E. DeBakey Fellowship in the History of Medicine. The fellowship provides up to \$10,000 to support onsite research in the historical collections of NLM, which span 10 centuries, encompass a variety of digital and physical formats, and originate from nearly every part of the globe.

Collections include the DeBakey papers—representing the diverse areas in which DeBakey made a lasting impact, such as surgery, medical education and health care policy—along with the papers of many other luminaries in science and medicine.

Anyone over age 18, of any academic discipline and status, who has not previously received this fellowship may apply. Non-U.S. citizens may apply. Group applications should be submitted under the name of a single principal researcher.

For details about the application process and required documents, visit the websites at <https://www.nlm.nih.gov/hmd/get-involved/debakey-fellowship.html> and <https://faes.org/DeBakey-Fellowship>.

To apply for the fellowship, submit all required materials to the Foundation for Advanced Education in the Sciences (FAES) via the online application portal, by midnight EDT, Sept. 30, 2021. Selected fellows will be notified and awards will be announced in December.



In an image from NLM’s online collection, Dr. Michael E. DeBakey performs surgery, circa 1981.

‘DISSECTING GENDER’



In 2019, Nemeroff gave birth to a healthy baby boy. "I'm so thankful for NIH and being part of the study," she said. The Children's Inn at NIH (shown at right) offered her family a place to stay together when she participated in clinical research as a youngster.



Inn

CONTINUED FROM PAGE 1

Bianchi during a virtual Children's Inn Discovery Session, a celebration of 30 years of hope and discovery. "It makes research that much easier and smoother."

The inn is "a place like home" for patients and their families, she said. After a day of medical appointments, patients can return to the inn where they can take part in a range of therapeutic, recreational and educational programs and services. Parents can talk with other parents who are going through similar challenges.

"The inn is a magical place," she said. "It provides an incredible improvement in the quality of life."

Patients staying at the inn have participated in clinical research studies that have helped NICHD researchers advance treatments for adrenal gland disorders, such as Carney Complex, Cushing's syndrome and Niemann-Pick disease type C, a rare, but fatal genetic disorder that causes a progressive decline in neurological and cognitive functions in children and adolescents.

NICHD researchers can learn something about a fundamental principle, such as

understanding changes at the DNA level, and then develop therapies based on that advance. "Our special sauce is the ability to take that from a basic science discovery and then apply it to something that directly helps people," Bianchi said.

Going forward, she said, NICHD is interested in studying the transition from childhood to adolescence. Many children with chronic illness don't receive the same level of care as they get older.

"I'm deeply grateful to the Children's Inn families and I'm heartened by their stories of resilience," she said. "I'm grateful that patients and their families show an incredible generosity of spirit by paving the path for future generations."



During a 30-year anniversary event, NICHD director Dr. Diana Bianchi said, "The inn is a magical place."

One patient is Kristal Nemeroff, a 33-year-old registered nurse and certified school nurse from Pennsylvania. She's been enrolled in an NIH clinical research study for osteogenesis imperfecta (OI) since she was 7 months old.

Also known as "brittle bone disease," OI is a rare genetic disorder that weakens bones significantly, leading to frequent fractures. People with the condition live with chronic pain due to the fractures.

Growing up, she traveled to NIH every 4-6 months. Before the inn opened, pediatric

patients like Nemeroff had to stay in hospital rooms. That meant staying in the hospital for up to a week with only one parent. The inn gave her whole family the opportunity to stay together. After a full day of doctor's appointments, she looked forward to going back to the inn's warm, familial atmosphere.

Her experiences at NIH inspired her to

become a pediatric nurse. CC staffers helped her come up with reasonable accommodation so she could succeed in school. She knew she wanted to help children with chronic illnesses achieve their full potential.

As part of her treatment, she received an experimental drug that increased her bone density by 21 percent and reduced her pain.

"I woke up one day and, about 3 weeks after the first infusion, I could feel the changes happening in my spine," Nemeroff said. "I didn't have nearly as much pain as I was used to having and it made middle school so much better."

The treatment she received is now standard for people with OI. Patients born 20 years after Nemeroff benefited from her participation in clinical research. "You're helping yourself in the short term and then you're helping so many people in the long term with the data that you're contributing to studies," she explained.

Enrolling in a clinical study is a big commitment, Nemeroff said. However, the inn makes it easier to participate in research. Residents can cook their own food, play games and be around other children who know what it's like to live with a chronic illness. Being at the inn "feels like home."

In 2019, Nemeroff gave birth to a healthy baby boy. "I'm so thankful for NIH and being part of the study," she said. "I don't think that I would be doing nearly as well as I'm doing in my adult life without all the intervention that they helped facilitate when I was young."

The session was one of four online 30th anniversary events that featured families, NIH director Dr. Francis Collins, institute and center directors and members of Congress. The other sessions can be viewed on the inn's YouTube page: <https://www.youtube.com/childrensinnorg>.

Gene Therapy Restores Immune Function in Children with Rare Disorder

An investigational gene therapy can safely restore the immune systems of infants and children who have a rare, life-threatening inherited immunodeficiency disorder, according to a study funded in part by NIAID, NHLBI and NHGRI.



A DNA double helix rests on a printout illustration of the DNA letters A, T, C and G.

IMAGE: DARRYL LEJA, NHGRI

The researchers found that 48 of 50 children who received the gene therapy retained their replenished immune system function 2 to 3 years later and did not require additional treatments for their condition, known as severe combined immunodeficiency due to adenosine deaminase deficiency, or ADA-SCID. The findings were published in the *New England Journal of Medicine*.

ADA-SCID, which occurs in approximately 1 in 200,000 to 1 million newborns worldwide, is caused by mutations in the *ADA* gene that impair the activity of the adenosine deaminase enzyme needed for healthy immune system function. This impairment leaves children with the condition highly susceptible to severe infections. If untreated, the disease is fatal, usually within the first 2 years of life.

A potential treatment option for infants and older children with ADA-SCID, “gene therapy is a one-time procedure that offers patients the hope of developing a completely functional immune system and the chance to live a full, healthy life,” said NIAID director Dr. Anthony Fauci.

People with ADA-SCID can be treated with enzyme replacement therapy, but this treatment does not fully reconstitute immune function and must be taken for life, usually once or twice weekly. Transplants of blood-forming stem cells, ideally from a genetically matched sibling donor, can provide a more lasting solution. However, transplants carry risks and most people lack such a donor.

The new research evaluated an experimental lentiviral gene therapy designed to be safer and more effective than previously tested gene-therapy strategies for ADA-SCID. This gene therapy, developed by researchers from UCLA and Great Ormond Street Hospital in London, involves

inserting a normal copy of the *ADA* gene into the patient’s own blood-forming stem cells.

The results come from 3 separate phase 1/2 clinical trials, 2 conducted in the U.S. and 1 in the U.K. The 50 children with ADA-SCID enrolled in the 3 studies ranged in age from 4 months to 16 years old. Most participants acquired and retained robust immune function following gene therapy—96.7 percent after 2 years in the U.S. studies and 95 percent after 3 years in the U.K. study—and were able to stop enzyme replacement therapy and other medications.

The lentiviral gene therapy appeared safe overall, although all participants experienced some mild to moderate side effects, mainly attributable to the chemotherapy the participants received during the procedure.

New Ultrasound Technique Detects Fetal Circulation Problems in Placenta

NIH-funded researchers have developed a new ultrasound technique to monitor the placenta for impaired fetal blood flow early in pregnancy. The method could help diagnose circulation problems in the placenta that can harm the fetus and would otherwise go undetected until late in pregnancy.



An NIH-funded advance could alert physicians to increased need for fetal monitoring, early delivery.

IMAGE: MONKEYBUSINESSIMAGES/ISTOCK/GETTY

The technique, which uses conventional ultrasound equipment, relies on subtle differences in the pulsation of fetal blood through the arteries at the fetal and placental ends of the umbilical cord, potentially enabling physicians to identify placental abnormalities that impair fetal blood flow and, if necessary, deliver the fetus early.

Researchers tested the new technique with ultrasound scans on women between the 26th and 32nd weeks of pregnancy and diagnosed those with circulatory problems in the maternal or fetal part of the placenta. After the women gave birth, the diagnoses were verified by comparing them to the results of physical examination of the placentas they delivered. Among them,

40 women had placentas without circulation problems, 16 had placentas with fetal circulation problems, and 30 had maternal placenta circulation problems.

The study, led by Dr. John G. Sled of the Hospital for Sick Children in Toronto and funded in part by NICHD, appears in *eBioMedicine*.

Researchers Wirelessly Record Human Brain Activity

Researchers are now able to wirelessly record the directly measured brain activity of people living with Parkinson’s disease and to then use that information to adjust the stimulation delivered by an implanted device. Direct recording of deep and surface brain activity offers a unique look into the underlying causes of many brain disorders. Until now, though, technological challenges have limited direct human brain recordings to relatively short periods of time in controlled clinical settings.

This project, published in *Nature Biotechnology*, was funded by NIH’s Brain Research Through Advancing Innovative Neurotechnologies (BRAIN) Initiative.

Deep brain stimulation (DBS) devices are approved by the FDA to manage Parkinson’s disease symptoms by implanting a thin wire, or electrode, that sends electrical signals into the brain. In 2018, the laboratory of Dr. Philip Starr at the University of California, San Francisco, developed a version of DBS that adapts its stimulation only when needed based on recorded brain activity. In this study, Starr and his colleagues made several improvements to the implanted technology.

“This is the first device that allows for continuous and direct wireless recording of the entire brain signal over many hours, while people are going about their daily lives,” Starr said.

The implications are significant. The new technology makes it possible to validate brain activity patterns in the real world, not just in clinical settings. Also, recording over long periods of time can now identify distinct changes in brain activity (biomarkers) that could predict movement disorders for individual patients. This paves the way for customized DBS treatments.

Researchers are working with participants to address privacy and other ethical concerns. “We have told patients to feel free to remove their wearable devices and to turn off their brain recordings whenever they engage in activities they would like to keep private,” said Starr.

One unforeseen benefit: Because the study required little to no direct contact with clinicians following surgery, it was ideally suited for social distancing that’s been crucial during the Covid pandemic.

Outgoing NCATS Director Austin Embraced Teamwork

BY TERRY RUDD

What's the essential ingredient shared by an opera singer and a translational scientist?

For Dr. Christopher Austin, outgoing director of the National Center for Advancing Translational Sciences, the answer is easy: teamwork.

"In music, you have to be listening to the other singers and instruments all the time, and you're constantly adapting to what the larger group needs," he explained.

Austin has pursued his full-time scientific career while singing baritone roles part time in professional opera companies. That same team-based approach is crucial in translational science, where experts across disciplines and with different skill sets, work together to accelerate scientific discoveries into clinical interventions.

Millions of people are waiting for safe and effective treatments, and translational science can help deliver them sooner. The field focuses on optimizing the complex scientific and operational processes that underlie each step involved in translating an observation or discovery into a solution to improve health.

Austin leaves NCATS to become a partner at Flagship Pioneering, a Cambridge, Mass.-based life sciences organization, and chief executive officer of a new Flagship franchise company focused on developing therapies for genetically complex diseases.



At left, Austin (r) sang baritone roles part-time in professional opera companies, including this performance in *Lucia di Lammermoor* with Baltimore's Opera Vivente. IMAGE: OPERA VIVENTE

At right, the NCATS director displayed his operatic talents at the 2018 NIH's Got Talent contest. IMAGE: MARLEEN VAN DEN NESTE

As NCATS director, Austin spent nearly a decade championing translational science and establishing it as a field.

His career has spanned the spectrum of translational research in the public and private sectors. He left Merck Research Laboratories to join NIH in 2002 as senior advisor to the director for translational research at the National Human Genome Research Institute, where he was responsible for developing research programs leveraging results of the newly completed Human Genome Project.



Dr. Christopher Austin served as NCATS director from 2012 to April 2021.

IMAGE: NCATS

While at NHGRI, Austin founded and directed the NIH Chemical Genomics Center, Therapeutics for Rare and Neglected Diseases program, Toxicology in the 21st Century initiative, and the NIH Center for Translational Therapeutics.

When NCATS launched in late 2011, Austin became the inaugural director of the Center's Division of Preclinical Innovation, and then was appointed as NCATS director in 2012.

Austin often compared translational science to systematizing serendipity. Paraphrasing a former mentor, he said translational science can help guide research out of the trial-and-error "zone of chaos" and onto more predictable, successful and shorter pathways to new treatments.

Just as understanding the rules of physics or chemistry unlocked breakthroughs in those fields, understanding the science of translation could revolutionize how discoveries turn into interventions that improve our health.

NCATS has used its understanding of translation and commitment to teamwork-based solutions to develop innovative research approaches and

technologies that work across scientific disciplines and diseases. These include tissue chips that speed drug research, automated drug repurposing, accelerated therapeutic discoveries for rare and neglected diseases, dozens of patents for pre-clinical innovations, and a nationwide network of clinical center partners to rapidly implement clinical trials in search of therapeutic solutions, including for Covid-19.

"Chris Austin is a great leader who commands, leads and inspires," said Dr. Geoffrey Ling, professor of neurology, neurosurgery, anesthesiology and critical care medicine at Johns Hopkins Hospital.

"NCATS has a unique mission of translating scientific advances into the clinic, and it's one that Chris embraced and worked so hard to meet," added Ling, who also has served as the director of the Defense Advanced Research Projects Agency Biological Technologies Office. "I am very grateful and proud to have worked with him on the NCATS advisory council."

The NCATS culture encourages risk-taking by focusing on solving problems through teamwork, and Austin worked to build a diverse team whose success is built on orchestra-like collaboration and camaraderie.

"Chris Austin genuinely recognized that happy staff are productive staff—and he made it part of his job to ensure the former, so the latter comes naturally," said Dr. Christine Colvis, director of NCATS Drug Development Partnership Programs.

Under Austin's bold vision, NCATS's primary goal has been to apply translational science approaches to improve the lives of people who need medical solutions.

"The most important element of any organization is for everyone in it to know why they're doing something," Austin said. "I wanted NCATS staff to have the patient with the disease as their reason for doing anything."

Patient partnerships are integral to NCATS's team-based approach.

"Chris Austin's commitment to progress for patients is unwavering and has meant the world to the patient community," noted Margaret Anderson, a managing director at Deloitte Consulting and a founding member of NCATS's advisory council and Cures Acceleration Network Review Board.

Austin's New England move inspired his mentor, NIH director Dr. Francis Collins, to pick up his guitar and play a take on Boston buskers' immortal *Charlie on the MTA*. (See it here https://twitter.com/ncats_nih_gov/status/1382749470211850242)

While Austin will be moving, he won't be trading his lifelong love of the Baltimore Orioles' Memorial Stadium and Camden Yards for a newfound Fenway Park fandom.

As Austin readily concedes, there are some fields even translational science will never unite.



DTR Training Program Again Earns AP Status

The Office of Research Facilities (ORF) supports NIH's mission by designing, maintaining and operating the facilities that house the agency's research, clinical and administrative functions. ORF's Division of Technical Resources (DTR) supports ORF through its training program, which provides architects, engineers and project officers with relevant courses taught by industry experts on topics including national code and standard updates, industry best practices and other technical skills and knowledge.

DTR's training program has recently been approved, once again, as an International Association for Continuing Education and Training (IACET) accredited provider (AP).

IACET is dedicated to setting the highest possible standards for continuing education and training, and the American National Standards Institute (ANSI) ANSI/IACET standard that APs follow is the backbone of leading educational programs worldwide. The DTR program is one of only 501 APs currently listed on the association's site and uses its accreditation to provide regular, high-caliber technical training for NIH'ers.

To earn AP status, DTR completed the IACET application process in 2010, which included a review by a site visitor, and demonstrated adherence to the ANSI/IACET 1-2007 standard regarding design, development, administration and evaluation of its

programs and record systems. The program has since maintained its AP status by submitting a comprehensive reaccreditation application once every 5 years.

As of the most recent reaccreditation, DTR is compliant with the current ANSI/IACET 1-2018 Standard.

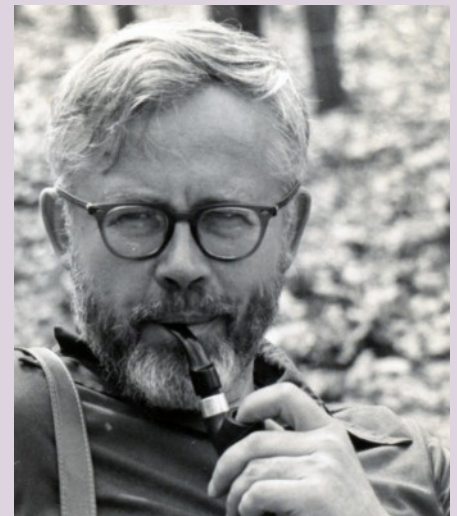
APs comply with the standard to hold rigorous, quality training events, and are the only organizations approved to offer IACET continuing education



The energy behind DTR's continued accredited provider status includes Nika Lilley, DTR training program manager, and Steve Breslin, DTR Standards and Policy Branch chief.

units (CEUs)—credits recognized by numerous institutions globally.

While the DTR Training Program is the only IACET accredited provider at NIH, training events are open to all NIH employees who are interested in registering. Additionally, groups who work with the program to host training events can benefit from its AP status to offer CEUs.



NICHD scientist emeritus Dr. Phillip G. Nelson

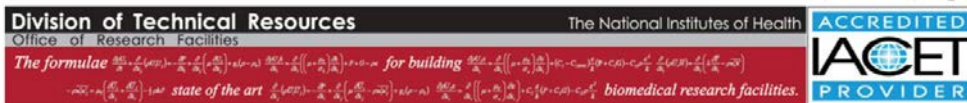
NICHD Mourns Scientist Emeritus Nelson

NICHD scientist emeritus Dr. Phillip G. Nelson passed away of natural causes at age 89, with his wife of 66 years, Dr. Karin Nelson, by his side. He headed the institute's section on neurobiology for 35 years until his retirement in 2004.

Along with Dr. Marshall Nirenberg, Nelson was among the first to show that cultured neurons could establish functional synapses and were suitable for a broad range of studies into the nature of neuronal transmissions. Much of his research focused on understanding how experience shapes the nervous system and how synapses function.

He contributed to many significant advances in the fields of neurophysiology and cell culture biology, publishing more than 200 papers in peer-reviewed journals. He also mentored dozens of trainees.

In addition to his wife, Dr. Karin Dermansly Becker Nelson, scientist emeritus at the National Institute of Neurological Disorders and Stroke, he is survived by 4 children and 11 grandchildren.



NIH Users should use their current NIH Login Username and password to login and register for classes.
For non-NIH users, download and submit form to create an account. [CLICK HERE.](#)



Technical Trainings are IACET certified courses taught by professional trainers and industry experts. The duration of most Technical Trainings range between 2 or more hours and/or multiple days. They are awarded professional development hours (PDHs) for attendance or continuing education units (CEUs) upon completion of an assessment. Technical Training topics include updates of national code and

DTR website features its IACET stamp of approval (upper right corner).



Clockwise (from above), Spa Flow instructor (I) leads crew in construction yoga, mindfulness meditation and breathing exercises.



Campus Contractor Celebrates Construction Safety Week with Yoga, Stress-Relief Activities

Hensel Phelps, a construction contractor at NIH, celebrated Construction Safety Week (May 2-7) while working on the NIA Center for Alzheimer's and Related Dementias facility (CARD), Bldg. T44, on the Bethesda campus. CARD researchers will work across scientific domains and disease boundaries to bridge basic, preclinical and clinical research with the goal of accelerating translational research on these devastating diseases.

The focus of Construction Safety Week was Total Wellness including mental health and involved several events such as "construction yoga" and mindfulness meditation.

According to its website, the week began in 2014 when 40 national and global building firms joined forces to "inspire everyone in the industry to be leaders in safety."

In 2016, the effort became an annual campaign focused on the original mission, which includes "conducting onsite safety awareness activities to support education."



Stress balls in the shape of the human brain to align with the mission of the CARD building were also part of Safety Week events.



CB Acai Café food truck offers choice of a healthy smoothie or acai bowl.



Above, Hensel Phelps construction crew members celebrate Construction Safety Week with a yoga instructor (kneeling) at the site of NIA's upcoming Center for Alzheimer's and Related Dementias facility—Bldg. T44. At right, they prepare to engage in "Daily Dynamic (active motion) stretch & flex."

